Injury – International Journal of the Care of the Injured
Volume 46, Issue 4, April 2015, Pages 564-571

Accepted: 29 November 2014
Published online: 9 December 2014
DOI: http://dx.doi.org/10.1016/j.injury.2014.11.035

Understanding and meeting information needs following unintentional injury: comparing the accounts of patients, carers and service providers

Authors: Blerina Kellezi[1], Kate Beckett[2], Sarah Earthy[3], Jo Barnes[4], Jude Sleney[3], Julie Clarkson[5], Steve Regel[6], Trevor Jones [7] and Denise Kendrick[8] on behalf of the Impact of Injuries Study group.

Author affiliations:
1. Division of Primary Care , School of Medicine, Nottingham University, University Park, Nottingham, UK. Electronic address: Blerina.kellezi@nottingham.ac.uk.
2. University of the West of England, Research and Innovation, University Hospitals Bristol NHS Foundation Trust, Education Centre, Bristol, UK
3. Department of Sociology, Faculty of Arts and Human Sciences, University of Surrey, Guildford, Surrey, UK
4. Loughborough Design School, Loughborough, UK
5. Nottingham University Hospitals, Nottingham, UK
6. Centre for Trauma, Resilience and Growth, Nottinghamshire Healthcare NHS Trust, Nottingham, UK.
7. Patient Representative, Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East Midlands, Nottingham, UK.
8. Division of Primary Care, School of Medicine, Nottingham University, University Park, Nottingham, UK.

Abstract:

OBJECTIVE: To explore information needs of unintentional injury patients and their carers over time, across services, and how such needs are met from the perspectives of patients, carers and service providers.

METHODS: Qualitative nested study within a multi-centre longitudinal study quantifying psycho-social, physical, occupational outcomes and service use and costs following a range of unintentional injuries. Semi-structured interviews conducted with 45 patients during the first year post injury, 18 of their carers and 40 providers of services.

RESULTS: Patients and carers needed information about the nature and severity of injury, prognosis, self-management and further services. Information needs changed over time with the biggest difficulties being during transfer from primary to secondary care. Barriers to information provision included service providers' time limitations and uncertainty around information provision, and patients' reluctance to ask for information or inability to process it. Suggested improvements included provision of reassurance as well as factual information, information about further services, earlier follow-up, increased appointment times and greater involvement of families where appropriate.

CONCLUSIONS: The information needs of patients and carers post injury change with time and there are a number of ways to remove gaps and barriers in current provision to meet such needs.

PRACTICE IMPLICATIONS: Providing information on injury management, prognosis and available services and reassurance at each stage of the recovery process in secondary care and when transferring to primary care would be helpful for patients and carers. A follow-up contact soon after discharge and the opportunity to ask questions could be beneficial. Better information about the patient's needs and ways they can help could help carers fulfil their caring role.

Keywords: Carer; Information needs; Information provision; Patient; Service provider

Introduction

Unintended injuries are a leading cause of disability worldwide [(1)] with wide ranging social, psychological, physical and economic consequences for patient, family, health services and society [(2-4)]. In the USA alone, in 2012, there were nearly 20 million ED attendances due to unintentional injuries among 15-69 year olds [(4).] Yet post-injury information needs and provision are poorly understood.

Within illness, the importance of information in increasing patient engagement in care and adherence to treatment is well established [(5)], as is the significance of family engagement in enhancing recovery [(6, 7)]. Studies demonstrate how lack of information inhibits patient involvement in treatment [(8)] and causes communication breakdown [(9)]. Barriers to effective patient-practitioner communication include conflicting information, lack of mutual understanding, mismatch between needs and provision, lack of aftercare and treatment information [(10-14)].

Most studies of post-injury information have focused on issues emerging from poor information provision [(15-18)] and links between inadequate information and patient anxiety and mental health [(17, 19, 20)]. Less is known about how patient and carer information needs change over time, provision of aftercare, treatment information or congruence between service provider, patient and carer perspectives.

This article presents analysis of qualitative data from the Impact of Injuries Study (IOIS) [(21)]; a longitudinal study in four UK centres of the social, psychological, occupational and economic impacts of injury among working aged adults (n=668). Patient, carer and service provider interview accounts are compared to identify gaps in information provision, contributory factors and to inform recommendations for practice.

Materials and Methods

Settings and participants

Semi structured interviews were conducted with a subset of injured patients (n=45) with lower or upper limb or multiple injuries, their carers (n=18), and providers of services used by patients (n=40) (see Table 1). Limb injuries were chosen to reflect the most common injuries experienced by study participants and multiple injuries to represent more severe injuries requiring greater coordination of care. All participants in the longitudinal study with these injuries were invited to participate in the qualitative study at one of three periods post-injury (1-4 months, 5-8 months or 9-12 months). We aimed to recruit four single limb injury patients per centre/period and an additional four multiple injury patients from one site per period. Maximum variation sampling using data collected in the longitudinal study (age, deprivation score, gender, social support levels (Crisis Support Scale), depression and anxiety (HADS), Post-Traumatic Stress (IES), alcohol (AUDIT) and drug use (DAST)) was used when more than four patients responded per centre/period. Interviewed patients were asked to identify a carer willing to participate in the study and all carers who volunteered were interviewed. Service provider sampling is described in full elsewhere [21, 22] and involved a variety of methods to gain broad coverage across services and levels.

Table 1: Characteristics of qualitative study participants

	Patients (n=45)	**Carers (n=18)**	**Service Providers (n=40)**
Type of sampling	Quota Sampling	All eligible identified by interviewed patients	Quota sampling
Actual recruitment			
Invited	169	27	500-700
Responded	72 (43%)	18 (67%)	47 (9-7%)
Participated	45 (27%)	18 (67%)	40 (85%)
Gender			
Men	21 (47%)	8 (44%)	N/A
Women	24 (53%)	10 (56%)	N/A
Patient injury type			
Lower extremity fracture	26 (58%)	10(56%)	N/A
Upper extremity fracture	8 (18%)	4 (22%)	N/A
Multiple injuries	11 (24%)	4 (22%)	N/A
Patient injury mechanism			
Falls/stumble/trip/jump	25 (56%)	10 (56%)	N/A
Road traffic collision	12 (27%)	4 (22%)	N/A
Other	8(18%)	4 (22%)	N/A
Time interval between injury and interview			
1-4 months	13 (29%)	-	N/A
5-8 months	17 (38%)	11 (61%)	N/A
9-12 months	15 (33%)	7 (39%)	N/A
Site			
Bristol	10 (22%)	7 (39%)	12 (30%)
Loughborough	8 (18%)	4 (22%)	6 (15%)
Nottingham	18 (40%)	5 (28%)	15 (38%)

Surrey	9 (20%)	2 (11%)	7 (18%)
Additional information	**Patients – age** Mean (SD) 52 (13%)	**Carers - relation to patient** Spouse/partner/ex-partner: 14 (78%) Other family member: 2 (11%) Friend: 1(6%) Employer: 1(6%)	**Service Providers - profession & specialism** Physiotherapists: 9 (23%) Occupational therapists: 2(5%) Nurses: 14 (35%) GPs: 3 (8%) Hospital doctors: 5 (13%) Osteopaths: 2(5%) Ambulance service personnel: 3(8%) Psychologist: 1(3%) Voluntary sector manager: 1(3%)

Interview schedules were developed through literature review, group discussions and previous research by the authors including the UK Burden of Injury Study [10, 23]. Schedules were piloted on 2 participants from each group and confirmed as fit for use. Pilot interviews were included in the analysis. Interviews with all participants explored similar aspects of information provision, needs and access. Service provider interviews additionally addressed individual and organisational barriers to better information provision. Patient and carer interviews were undertaken in the participant's home or by telephone. Service provider interviews were conducted at the participant's place of work or by telephone. Interviews lasted from 30 minutes to over two hours; their content was audio recorded and centrally transcribed.

Analysis

The audio-recorded interviews were analysed using thematic analysis based on the methodology described in Braun and Clark [24] supported by Nvivo 10 software. A coding frame for each type of interview was developed iteratively by the paper authors (who include a service user) through cycles of independent coding, discussion and comparison. Initial coding was followed by secondary level coding including inter-coder reliability testing of 10% of the data. Themes were grouped and

tabled into categories for each transcript. Continuous discussions took place among the authors to identify discrepancies and disagreements and discuss emergent themes**.**

Results

The patient and carer perspective

Patients and carers described wide-ranging information needs relating to both the injury and its impact on their lives. In addition to the medical explanations routinely provided by health professionals, patients and carers sought: guidance about the extent of physical exertion permissible or required; information about the significance of symptoms and guidance on when to seek medical advice; reassurance about what was 'normal' following their type of injury and prediction of timescales for and extent of recovery. These information needs changed during treatment and rehabilitation but were particularly acute during early days at home when opportunity to access information was much reduced.

The service provider perspective

Service providers were generally aware of the diverse types of information and reassurance sought by patients and carers and some acknowledged patient difficulty in absorbing information or asking questions. Inadequate informational support was attributed to operational pressures and constraints. Perceived limits to their professional role/expertise and the difficulty of predicting recovery from serious injury were also significant themes.

The following sections explore information needs and provision in patient, carer and service provider accounts at specific points in recovery or in relation to particular aspects of treatment.

Information provision in Emergency Departments

Service providers reported that factual information about the severity of injury, immediate treatment and the need for admission was routinely provided in the emergency department although time to respond to questions was limited:

> "They need the right treatment and … to understand what's happening to them and to be listened to, questions actually answered … they need time." (Specialist nurse)

Patient and carer accounts generally supported these service provider views:

> "this young doctor came and he actually spelled out exactly what it was and he drew […] the pelvis and where the cracks were.. to show her where the fall had been" (Husband of female patient: 68, lower limb injury)

However, patients and carers were often unable to take in much of the information provided at that stage particularly when the extent of injury was severe or uncertain:

> "the doctor came in and told us …about her injuries. He said she had a split liver and all these internal things. He was ranting all this stuff off [...] She had been cut out of the car and she had been sedated at the scene and they were telling us all that … by then I was … a wreck." (Mother of female patient: 29, multiple injuries)

The revision of an initial medical assessment could be confusing for patients and non-specific reassurance misinterpreted as a clinical assessment if supplied by a doctor:

> "So anyway when the doctor came … he said he thinks I have ruptured the patella tendon and then he went away … and … another doctor (visited) some while later and he said you know what's happened and I said 'I think I have ruptured my patella tendon' and he said 'No you haven't." (Male, 57, lower limb injury)

Information provision in relation to surgery

Most patients commented positively on the information provided prior to surgery:

> "He was very clear, very concise and very matter of fact and he said this is what we've got to do and explained roughly how they would do it and what it would mean and he did discuss the long term impact with me as well, and I took it, at the time… all on board, … I knew what was going to happen and roughly what would happen afterwards in the timescale, very roughly and then this registrar did all the same things again, word for word, so I was aware of what was going to happen." (Female, 51, lower limb injury)

However, information about postponed operations was generally poor:

> "nobody came and explained why I'd been cancelled. I was quite upset about it […] If one of the sisters had come and …talked to me and told me why I was being cancelled every time I would have understood. But "you're cancelled, what do you want to eat?" I don't think that's good enough personally." (Female, 69, multiple injuries)

Some service providers acknowledged the negative effect of cancelled operations on patient morale but none of the study centres had processes in place to ensure that patients were given timely information and explanation as a matter of course.

> "There's a big board and it has all the patients on it and they kind of plan who's going to theatre when … And unfortunately I think that doesn't always get back to the patient. They kind of think 'oh I'm waiting, waiting, waiting, why am I not going to theatre?' That can be quite challenging particularly when there are outlying orthopaedic wards, they [patients] might get starved every day even when we know …. there's no hope of them going to theatre today." (Trauma and orthopaedic nurse)

Information post-surgery tended to focus on the outcome of the procedure rather than a broader discussion of what patient might expect over the coming weeks:

> "Yeah, someone came up, it was the registrar …. very efficient humourless young man …. he just explained that it had all gone very well and they were all very pleased and it was all going to be marvellous and …that was about it really." (Female, 51, lower limb injury)

The capacity of patients to take in information was sometimes overlooked; for example, a number of patients were informed about the outcome of surgery whilst still in the recovery room:

> "the surgeon came around and started talking at me… and I was struggling just keeping my eyes open and he ….said I am informing you how things went." (Male, 36, lower limb injury)

Other patients had to wait until an out-patient appointment for detailed information about their surgery:

> "I'm not expecting them to sit there for half an hour.. but I think three or four minutes, just to say this is what we did, it was successful… When I got the real detail was two weeks later in the clinic. (Female, 61, lower limb injury)

Information provision on the hospital ward

Concern that they were or might be viewed as a nuisance featured in many patients' accounts of their time in hospital and discouraged proactive information-seeking:

> "you're in an unusual environment and you're not quite sure what you should ask and what not. Obviously they've got lots of people to see, you don't want to hold them up all the time but you're trying to get the information that you're after. I think you just get that feeling I'm a bit in the way… well I didn't want to say anything to upset anyone or… get moved out of the hospital before I'd been treated thoroughly." (Male, 37, lower limb injury)

Many patient interviewees would have liked to have discussed their injury with a health professional while in hospital but few had been able to do so:

> "it would have helped … somebody who knew things sparing the time to sit down to talk to me and listen to my questions … there was never anybody …, who could talk to me … an intelligent person rather than a nuisance of a body in a bed" (Female, 70, upper limb injury)

Carers also described variations in the adequacy of the information provided. Some had received only vague communication about how long the patient was likely to stay in hospital, which made it difficult to plan, while others had little warning before the patient was discharged.

Hospital nursing staff were generally aware of patients' diverse information needs extending beyond immediate treatment to longer term considerations of the consequences for their lives. However scarcity of time frequently prevented staff from fully engaging with these needs even to the extent of deliberately avoiding such conversations:

> *"Staff don't always have that time to give to the patient … the pressures are on the bed and the staff know it … so you daren't ask (the patient) a question in case you get held up." (Senior nurse)*

Returning home and rehabilitation

Coming home from hospital was an anxious time for all the patients interviewed. Most felt that they had received insufficient information about managing their injury, what to expect, timescales of recovery or potential sources of help:

> "they … said 'yes that looks alright, … you can go home',… they did not say 'when you get home do this, that, the other'. Nobody told me anything about changing the dressings or anything like that." (Male, 57, lower limb injury)

This anxiety was shared by many carers who were unsure what they could or should do to support the patient or what services were available:

> "I didn't know if I was doing the right thing or not and I didn't know… how much she should be allowed to do herself and how much I should be helping her." (Husband of female patient: 68, lower limb injury)

> "We just kind of dealt with the situation as it presented itself. Nobody ever advised us that there were any services available." (Wife of male patient: 36, lower limb injury)

A minority of patients had received clear and specific information prior to discharge, which was much valued particularly when combined with the possibility of asking further questions if needed:

> "She told me what to do about [scar healing]. she was very clear… rub the scar tissue … keep massaging it …she … reassured me that it would go down … I felt I could ask her

> anything and she would give me a very sound and reassuring answer." (Female, 54, lower limb injury)

> "The consultant came and had a chat with me and told me what to do and what not to do and to be very careful with certain things and obviously I'd got an open door if I'd got any problems." (Male, 59, multiple injuries)

Staff in a specialist burns unit were better placed to prepare patients and carers for return home due to the higher staff-patient ratio, regular post discharge contact, and greater familiarity with patients and their families due to longer length of stay:

> "If you're in hospital and you've got … family members here and they're listening and they're learning and they're taking it all on board, when you go home you've still got that network of people that were … involved in your care and … in the early stages." (Nurse, Burns Unit)

The timing of the first follow up appointment varied greatly between the four study sites, ranging from 2-6 weeks. Patients were usually seen by a member of the orthopaedic team. For patients who had left the hospital without clear information about their treatment and injury management, this appointment was an important opportunity to seek information and reassurance. However the time allocated for an appointment often did not allow it:

> "The thing that I think was missing the most was information and a bit of contact… probably seven to 10 days after the incident so when the swellings and bruising … are coming out … just to give you the options and let you be aware of what is available… with hindsight, I think would have assisted and accelerated the recovery period. (Male, 57, multiple injuries)

> "a lot of patients have been in there two minutes in the clinic, and the doctor's been in and out and they're not really a lot wiser." (Physiotherapist)

Poor communication between disciplines and settings had consequences for treatment and for the information provided to patients:

> "The physio… was excellent. The only thing that I was very miffed at was when I first went to see her; she had … no knowledge of what my break was." (Female, 52, lower limb injury)

> "he came to see me with the interpreter because he had on-going problems with pain and restrictive movement but I had no documentation from A&E … he told me …he had … been to a fracture clinic appointment but again I didn't have the information from the fracture clinic […] I felt bad for the patient who had made the effort of having a double appointment … (but I couldn't) make the most of that time because I didn't have that background information." (General Practitioner)

When the advice given by one health professional was later contradicted by another, patients feared they had unknowingly jeopardised their recovery:

> "I did get quite a lot of contradictory information when I was going for consultations after my operation. For instance when they thought my medial ligament was damaged, 10 days after I'd had the operation … I saw a different surgeon other than the one that I'd predominantly seen throughout. He told me I could start walking and it was only when my [rugby] club touched base with my surgeon that he said 'he shouldn't be walking … get him back off his feet'. … I'd been walking round all weekend." (Male, 20, lower limb injury)

Some service providers, in particular physiotherapists, recognised their role in helping patients define, cope with and accept a 'new normal' while their body healed and that this need potentially extended to family members:

> "I think they need to understand that what they are feeling and experiencing is in most cases entirely normal." (Physiotherapist)

> "A lot of our patients are upset about that. They feel their husband or wife doesn't understand why they're not functioning better and that sort of thing. So it's helpful for them to be in with us sometimes and you can talk." (Physiotherapist)

Patients were anxious to know the likely duration of incapacity because of work, childcare or other responsibilities. Yet such questions were difficult for service providers to answer because of uncertainty around recovery processes and reluctance to distress patients:

> "It was very difficult when he was trying to tell his employer how long he would be off." (Female partner of male patient: 29, lower limb injury)

> "Knowledge is power I think … discussing prognosis is really important and being realistic. But not giving them a doom and gloom prognosis … and that's really difficult you know sometimes." (Physiotherapist)

It was evident from patient and carer interviews that the emotional and psychological impacts of injury were often significant and unaddressed. Hospital based service providers perceived that NHS psychological support was limited and often had little information about other agencies or services:

> "We don't use any … support groups… with acute injury actually or even with multiple injury … I'm sure there are some out there, but that's not something we would signpost our patients to use." (Physiotherapist)

Barriers to information provision and ways to improve the services

All three groups identified barriers contributing to poor communication and lack of information (see Box 1) and suggested ways that information provision could be improved (see Box 2).

Discussion

Following hospital admission for an unintentional injury, patients and carers needed a range of information to understand the nature, severity and prognosis of the injury, assist in managing it, reduce anxiety, permit future planning and know what services they could access and how. This supports previous findings on the information needs of this group of patients [10]. Despite service providers having a generally clear vision of patients' information needs (less so, those of carers), most patients and carers interviewed had experienced information provision that was confusing, inconsistent, insufficient or mistimed. Information needs and ability to process information varied across different stages post injury. In the emergency department patients and carers needed factual information about severity of injury and treatments required but had difficulty processing this information. During the hospital stay there was a lack of information about surgical delays and at times information was vague or lacked sufficient detail about longer term considerations and impact on the patients' and carers' lives. During transfer from secondary to primary care there were significant gaps in information about injury management, prognosis and potential sources of help. Contradictory advice and poor communication between services had consequences for treatment and recovery. A list of information needs at key times is provided in Box 3.

Box 1: Factors contributing to poor communication and lack of information from service provider, carer and patient perspectives

Service provider barriers:

- lack of consideration of the full range of patient and carer information needs at different time points
- time constraints
- lack of adequate accessible information
- uncertainty about how much information to give
- conflicting opinions and information

Patient and carer barriers:

- reluctance to bother staff whom they perceived as being under pressure
- being under stress and in shock, or
- not knowing what questions to ask
- individual differences in patients' and carers' ability to absorb, hear or utilise information.

Organisational barriers:

- poor communication within hospital settings
- poor or lack of communication between secondary and primary care services
- lack of post-discharge information and support (e.g. telephone information line or follow-up contact)

Box 2: Suggested ways to improve information provision

a. Use of varied means of communication

All three groups recognised the importance of using different means (visual, face to face and printed) to provide information and involvement of different professionals in understanding and retaining information:

> "because people take things differently, … in an ideal world you'd see the doctor, get the clinical bit sorted out and then you would then see some sort of health advisor who would then explain exactly what's going to happen to you, what the difficulties are you're going to have, give you some information about how you can access them and then they would back that up with some sort of written information. So that you can then read it after you've left." (General Practitioner)

b. Professionals providing more emotional support and reassurance

Patient and carer desire for more caring and supportive interactions with service providers was evident throughout the interviews and at different stages post-injury:

> "You know supportive, that's all you need I think, the support and somebody to tell you you're alright, this is normal you know." (Female, 69, multiple injuries)

c. Provision of more factual information addressing a longer timescale

Patients and carers needed specific information about the present situation and guidance on what to expect in the medium and longer term in order to plan how to best manage the impact of the injury on their lives:

> "to make sure they understand what's happening, to make sure they are comfortable and pain free and their injuries are being treated and looked after, but actually that they have that level of information so that they can, if they're able to, can start to make some plans for what needs to happen. … It's being able to manage the expectation of the patient and what's going to happen after their fracture and how long are they going to be off work and how long, you know, are they going to need to be in hospital?" (Trauma and orthopaedic nurse)

d. Explaining procedures and their usefulness

Engaging patients in their own care and explaining why procedures are useful or the consequences of not following them in order to increase compliance and reduce anxiety:

> "If you can really explain to somebody 'well look, this is not going to get better because of X, Y and Z'.. They might not like it but they accept it. Whereas the big frustration often for patients is… they're just being told by their doctor what there's to do, they're not being allowed to make decisions. That's usually when people become a bit angry or frustrated and annoyed and tend not to cope as well with their problem. Whereas if they feel…like they are being involved and they know what's going on, then they accept things a lot better that way round." (Trauma and orthopaedic physiotherapist)

e. Longer appointment times

Allowing patients more time with service providers to provide information, answer questions, receive reassurance and better understand recovery:

> "So she has shown me pictures of how an operation is done, live pictures of an actual operation. So you have got more of an understanding of what's happening and how it has been done and why it has been done so you feel much more part of the process." (Male, 36, lower limb injury)

f. Involving families and friends

Including families and friends (with the consent of the patient and when appropriate) not only in managing the injury but also supporting the patient during recovery.

"By keeping people informed about what we're doing and the plan of their care, and their relatives, it's not just the patient, it's their relatives as well, then we can resolve lots that could potentially be issues." (Burns Unit nurse)
g. Follow-up appointments Providing a contact person or support line for patients following discharge or a health professional proactively following up patients at home: "maybe a follow up phone call a couple of days after the patient was back to say 'is the perching stool a good idea? Is there anything else that could help that we might be able to provide?" (husband of female patient: 70, upper limb injury) "it would have been nice for me personally just to have maybe have had a recall and been checked over. Or just to had a word at the hospital from the physio just to say look this is what you've got to do and or this is what you shouldn't do. And this is what you should expect. " (Male, 50, multiple injuries) "Somebody could have just come round and just sort of… advise me on stuff I could do or how I could make it easier … because I was like 'are there any exercises I could do at the house to make myself stronger?' and they were sort of like 'not much'." (Female, 33, lower limb injury)

Our results demonstrate a number of barriers to effective information provision. Those relating to service providers included conflicting information, time constraints, uncertainty about how much information was necessary and appropriate, lack of readily available information resources and lack of efficient inter-service communication. Patient reluctance to ask questions and inability to process information especially under stress were additional barriers. Patients and carers valued but often lacked opportunities to talk to health professionals to gain reassurance or specific types of advice. Participants suggested potential ways to improve information provision: use of diverse means of communication, provision of a greater range of factual information, reassurance about longer term issues, information about other services, earlier follow-up and increased length of appointments, a post-discharge telephone call, greater involvement (with the patient's consent) of families and friends, and improved inter-service communication. Consistency of findings between patient, carers and providers on information needs, problems with current provision and means to improve communication adds strength to these findings.

Our analysis benefits from diversity of participants. Patients and carers varied in terms of types of injury, the time elapsed between injury and interview, their domestic situation and other socio-demographic characteristics. Service providers came from a range of services. The study might have benefitted from social care and community service provider perspectives but these proved difficult to recruit.

Practice Implications

Injured patients have specific information needs at particular times after their injury as described in Box 3. Current services do not always meet these needs. There is a range of ways in which patients

could be provided with, or could be encouraged to seek timely information, relevant to their needs. Verbal communication from service providers could be reinforced with written information and with access to telephone or online information and advice. Leaflet or other written information would also support clinicians to provide information in a time-effective way. Patients and carers could be facilitated in their information seeking by the provision of questions they want to ask their service providers. Service providers could use checklists at key contacts to ensure important information needs at specific points in the recovery process are covered. A patient leaflet was developed based on the findings of this study, with specific information for services in the Southwest of England. A copy of the leaflet can be found on http://foi.avon.nhs.uk searching for *'Help yourself to recover: Going home after accidental injury'* Information checklists could also be an essential tool in providing information to patients at particular time points to enable them to better understand potential harms and normal recovery.

A follow-up contact soon after discharge, possibly by telephone, and the opportunity to ask questions could be beneficial. This would offer reassurance to the patient; help identify additional information needs with regards to follow up or access to other services; or address essential questions on how to deal day to day with the injury.

More attention should be paid to the emotional impact of the injury and its aftermath. Providing information and reassurance at each stage of the recovery process in secondary care and when transferring to primary care would be helpful for patients and carers. Follow-up contact would also enable patients to discuss the emotional impact of their injury and who to contact if these become persistent, pronounced and/or interfere with recovery. Carers can assume a central supportive role following discharge and this could be enhanced by better information about the patient's needs and ways they can help. In addition, involving carers (with the patients' permission) during the provision of information offers an additional source of reference for patients.

Case managers are used in some post-injury services in the UK to coordinate rehabilitation, care and support of people with complex clinical needs, for example, those with brain or spinal cord injury. Case managers are also used more widely in post-injury services outside the UK. They can play a vital role in information provision and extending case management to a wider range of injuries in the UK is likely to help meet patients' information needs. The case manager roles can be integrated within existing systems. For example, discharge nurses are utilised in many hospitals to co-ordinate a smooth discharge for a number of care pathways including hip fracture. The extension of the discharge nurses role to coordinate all trauma / orthopaedic discharges would ensure all patients benefit from having appropriate information at the point of discharge.

In addition, amending routine procedures and extending clinical roles to incorporate the information needs of patients in an obvious way would not create a greater workload. It would instead enhance effective communication channels between patients, service providers and carers.

Box 3: List of information needs at different time points

The information needs listed below could be met by: • A leaflet addressing the points below provided to all injured patients admitted to hospital • Separate leaflets to be given at key patient contact times, e.g. admission, discharge from hospital, at first physiotherapist or fracture clinic appointment, at first GP appointment. • Leaflets should include prompts (or a list of frequently asked questions) to help patients and carers formulate questions to ask on contact with service providers • A checklist of topics provided to service providers to cover at key contacts with patients.
Information required during emergency department attendances: • Factual information about severity of injury • Need for treatment and hospital admission • Further tests or examination required to establish the nature of their injury and treatment • Repetition of information at different stages to ensure retention
Information required pre or post-surgery: • Preparation and planned timing of surgery • Planned procedure, potential risks and factors which might necessitate alternative approaches • Explanations about changes to planned timing such as cancellations and delays • The likely effect of surgery and impact on patients short and long term functioning (physical, psychological, occupational, social) • Repetition of information at multiple contacts to ensure retention
Information required during hospital admission: • Estimate of length of hospital stay • Short and long term consequences of their injury • Services that can be provided during hospital admission (e.g. physiotherapy, occupational therapy, dietetics, counselling, etc) • Emotional support to assist in adapting to post-injury life and reassurance with regards to 'normal' psychological reactions to injury
Information required at discharge from hospital: • Guidance on how to manage the injury e.g. pain control, dressings, exercises, etc) • Guidance about activities that can and cannot be undertaken in short and longer term and how patient can judge when they are ready to return to activities (e.g. weight bearing, driving, activities of daily living, sports, hobbies, work, caring responsibilities, etc) • Significance of (physical and psychological) symptoms and when to seek medical advice • What constitutes normal recovery and timetable for and likely extent of recovery specific to patient's injury • Sources of help and support in primary care, community and voluntary organisations • Likely timetable of future appointments with services post hospital discharge

Conclusion

Despite service providers having a clear understanding of the information needs of injured patients which is largely consistent with patients' and carers' own perceptions, there are major gaps in current information provision with potential consequences for physical recovery and post-injury social, economic and occupational outcomes; and psychological distress. This article identifies particular stages in the recovery journey where information is important, barriers inhibiting current provision and makes recommendations for improvement. Some of the recommendations would seem to add to the burden of already stretched practitioners. The challenge is to ensure that these

findings are implemented into practice to optimise the potential for information to assist in recovery.

Funding: This research was funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care for Nottinghamshire, Derbyshire and Lincoln-shire (CLAHRC NDL). The views expressed in this work are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

Conflict of interest: All the authors declare they have no conflict of interest.

Acknowledgements: The authors wish to thank all patients, carers and service providers who took part in our study and Marcus Barker and Emma Rowley for conducting some of the interviews and their contribution on study design and analysis.

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